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ABSTRACT

Adult day care, a community-based group program designed to meet the needs of functionally impaired adults through an individual plan of care, is being considered by many communities seeking care options for their most frail and functionally impaired adults. In 1969 there were only a dozen adult day care centers in the United States, today there are over 1,400 centers. In 1979, the National Institute on Adult Daycare (NIAD) was established as a National Council on the Aging (NCOA) professional unit to provide a focal point for adult day care at the national level. NIAD conducted a nationwide survey of adult day care centers (N=847) in 1985. Preliminary results showed that 85% of respondents ranked the provision of an alternative to premature or inappropriate institutionalization as one of the top three objectives of adult day care. Other highly ranked objectives were maximization of functional capacity and provision of respite for caregivers. The majority of centers (74%) reported being private, nonprofit agencies. While many centers reported having at least one license, only 15 states have standards for licensure. Other findings focus on center locations, referral sources, number and characteristics of participants served, exclusions from participation, services provided, costs of adult day care, changes to participants, and level of participant functional impairment. (NB)

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ADULT DAY CARE
A NATIONAL PERSPECTIVE ON THE STATE-OF-THE-ART

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at the
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It is my pleasure to be here, representing the National Council on the Aging (NCOA) and its National Institute on Adult Daycare (NIAD). NIAD was established as an NCOA professional unit in 1979 to provide a focal point for adult day care at the national level. The institute was organized to promote day care as a viable option of a community-based program of services and activities for disabled older persons within the larger continuum of long-term care. Before I describe NIAD's most recent effort in the day care arena, let me cite the national definition of adult day care (especially for you who may be uninformed or misinformed):

> Adult day care is a community-based group program designed to meet the needs of functionally impaired adults through an individual plan of care. It is a structured, comprehensive program that provides a variety of health, social and related support services in a protective setting during any part of a day but less than 24-hour care.
>
> Individuals who participate in adult day care attend on a planned basis during specified hours. Adult day care assists its participants to remain in the community, enabling families and other caregivers to continue caring for an impaired member at home.

Contrary to what some people say, adult day care is not the "new kid on the block." Day care is a program whose "time has come." It is getting more attention than ever before, not only because established programs have proven the test of time but because communities are more aggressively seeking care options for the most frail and functionally impaired adults.

In 1969-70, there were a dozen adult day care centers in the United States. By 1977-78, nearly 300 programs had been identified by the Health Care Financing Administration. By 1980, HCFA published a national directory listing more than 600 adult day care centers. The growth between 1978 and 1980 indicated that day care was becoming accepted and utilized as a valuable modality of care. What is particularly remarkable is that the growth occurred despite the lack of a solid funding base. Communities obviously were working hard to make day care services available to their elders. Communities have continued to develop adult day services; today NIAD identifies more than 1,400 centers across the country. The grassroots evolvement of adult day car has produced a rich diversity of programs, reflecting the variety of different communities served.

In order to provide accurate basic information about extant adult day care centers, NIAD undertook a nationwide survey in October 1985. Funding provided by Shell Companies Foundation, New York Life Insurance Co., and NYNEX Corp. enabled the research. NCOA/NIAD contracted with On Lok Senior Health Services of San Francisco to analyze survey returns, prepare a summary report and establish the computer data base. On Lok's efforts were partially subsidized by a grant from the Henry J. Kaiser Family Foundation.

Analysis of survey responses has thus far been limited to frequency, mean, percentage and range. Cross-tabulation will occur in Phase 2 (indepth analysis phase). One of the

major research efforts of Phase 2 will be an attempt to find an acceptable basis for division of all adult day care programs into subgroups. In the initial analysis phase, all ADC programs are analyzed as one group. Much has been said in past research about various models of adult day care. We are not sure if the old distinctions really exist. We plan to examine this question from various viewpoints in Phase 2.

Response Rate

Responses were received from 847 centers. To compensate for duplication in the 1400 NIAD/NCOA surveys mailed out, On Lok compared its response rate to the NIAD 1985 survey of state agencies that monitor ADC. This state survey identified 1155 programs in 49 states. Programs with no state funding or programs located in states with no licensing requirements may not have been included. A conservative estimate is that at least 1200 ADC centers exist in the United States today. Responses from 847 centers is a 71 percent response rate if 1200 ADC centers are estimated, or a 61 percent response rate for the 1400 surveys mailed out.

My time today doesn't allow me to address all questions asked in the survey. So I have selected some in which you may have the most interest.

But first I'd like to give you a thumbnail profile of today's ADC centers.

Profile

The participant is Caucasian, female, 73 years old, has an average income of $478, and lives with his/her spouse, relatives or friends. One out of two needs supervision, and one out of five needs constant supervision. Almost one out of 13 is incontinent to the degree that changing is required while at the ADC Center. One out of 13 is behaviorally disruptive. Nearly one out of 10 is developmentally disabled. Almost one out of five relies on a walker or cane, and about one out of eight is wheelchair-bound and cannot transfer without assistance. The participant spends about six hours at the ADC center on the days he/she attends.

The average ADC center operates approximately five days per week, Monday through Friday, and serves 19 persons per day with a total enrollment of 37. The ADC center is nonprofit and is likely to share physical facilities with other programs. Services directly provided include social services, nursing, recreational activities, exercises, art, music, reality therapy, and dressing/grooming/toileting assistance. The center either contracts or directly provides meals and transportation, and may also provide or contract for physical, speech and occupational therapies, and diet counseling. Referrals are most likely to be made for physician, psychiatric, podiatric and dental services.

Where Are Respondents Located?

California, with 84 responses, has the largest number

responding to the survey. No centers from Idaho, Montana, Mississippi, New Hampshire and West Virginia responded to the survey. Approximately 31 percent of the respondents are located in four states:

California (84)	Massachusetts (65)
Florida (56)	Minnesota (61)

What Are the Major ADC Objectives?

There is a consensus of opinion regarding the primary objectives of adult day care. Centers were asked to rank objectives in order of importance. Our analysis covered objectives ranked first, second and third. eighty-five percent (85%) of the 847 survey respondents identified "to provide and alternative to premature or inappropriate institutionalization" as one of the top three objectives.

Second choice was "to maximize functional capacity," with 63 percent identifying this objective, followed by two close contenders for the third priority objective: "to provide respite for caregivers" (55%), and "to provide psychosocial supportive services" (53%). Other possible choices not appearing as top priorities were: "to provide rehabilitation" (13%); "to provide family counseling" (3%) and "other" (5%).

Who Provides Adult Day Care?

Centers were asked to state program auspices, i.e., profit/nonprofit and public/private status, and whether or not they were incorporated. Responses from 834 centers

showed that the overwhelming majority (74%) of the centers reporting are private, nonprofit agencies. Nine percent (9%) are operated by public agencies and seven percent by both government and private nonprofit agencies. A small percentage (10%) are operated by private for-profit agencies. Approximately 58 percent are incorporated.

Where Are ADC Centers Located?

This question was asked about the physical location (not organizational structure). The intent was to learn how many centers were in buildings primarily used for adult day care and how many shared facilities with other agencies, and if so, with whom.

Approximately 151 centers are in buildings used primarily for adult day care.

The remaining centers share facilities most frequently with: nursing homes (22%) and church buildings (17%). The large number in "Other" (25%) indicates the great variety of ADC settings. Additional categories should be added in the next survey taken.

PHYSICAL LOCATION
(N=790 responses)

Category	N	%
Hospital	38	5
Nursing Home	173	22
Senior Center	98	12
Church Building	143	18
School Building	26	3
Community Center	59	7
Clinic	18	2
Home Health Agency Office	10	1
Board & Care (Residential)	13	2
Other	212	27

Are ADC Centers Licensed?

A license is usually issued by state or county government and signifies to the public that the center has met a defined set of standards. However, the NIAD State Survey found only 15 states with standards for licensure: California, Florida, Hawaii, Kentucky, Louisiana, Maryland, Minnesota, Missouri, New Jersey, Pennsylvania, South Carolina, Texas, Utah, Virginia and West Virginia. Even states with licensing requirements may only require a license for certain types of day care programs and may allow the parent agency license to suffice. Centers may also possess several licenses. Four hundred and fifty-nine (459) centers or 57 percent of the 805 responding, stated they have at least one license.

Three hundred ninety-three (393) of the 459 licenses centers indicated they have a license for either adult day health care (210) or adult day care (social model) (183). Other types of licenses possessed are: outpatient clinic (22); nursing home (59); hospital (12); home health agency (9); outpatient rehabilitation (19); board and care (10); and other (44).

Three hundred forty-six (43%) respondents indicated they have no license and many wrote on their surveys, "There is no licensing requirement in our state."

Centers are licensed by a variety of agencies, sometimes more than one. States have many names for departments

working with health and social services. Some have umbrella agencies such as Human Services or Human Resources. As this was an open-ended question, we use "health" and "social services" in a generic sense; for example, the Department of Economic Security is considered as "Social Services/Welfare." Not all centers that indicated at least one license responded to this question. The Health and Social Services/Welfare Departments are the most frequent licensing agencies.

Where Do Referrals Come From?

Centers were given a list of various types of referral agencies and asked to rank them in order of importance. The choices were: health agencies, social service agencies, hospitals, churches, board and care, community physician, family/friends/word of mouth, senior centers, media and others. Our analysis totaled responses for the top three referral sources.

The primary referral source is quite clearly social service agencies, with 533 centers (63% of survey respondents) marking this item as one of the top three. The second ranked referral source is family/friends/word of mouth as identified by 506 centers (60%), followed by health agencies (399 centers, 47%).

Although not one of the top three referral sources, hospitals (257 centers, 30%) and community physicians (179 centers, 27%) are significant referral sources.

How Many Participants Are Served?

The average daily attendance given by 772 centers is 19 persons per day. Average total enrollment for the 648 centers giving this information is 37. On an average day, 14,748 persons receive adult day care at the 772 centers giving this information, with a total enrollment of 27,176.

Who Do ADC Centers Serve?

Adult day care is assumed to be an adult program. Therefore, three centers that serve persons younger than 18 were excluded from the analysis and will be analyzed separately in Phase 2.

Age is influenced by the fact that a subcategory of programs serve only adults under 65 (usually they are targeting developmentally disabled or mentally disabled participants). Funding sources often influence participant eligibility and may limit eligible persons to those over 60 or 65. Overall, age ranges from 18 to 110 years. Phase 2 will look at age differences at centers in depth. However, often it was noted that younger, disabled persons were accepted on a case-by-case basis.

Two-thirds of the ADC participants are female, which is not surprising as females outnumber males in the elderly population.

The number of centers responding to Average Monthly Participant Income was low. Only 370, or 44% of total respondents, answered this question. Some respondents

misinterpreted the question and gave a figure that looked more like the center's monthly budget than a participant's income -- this date was not entered. Many centers wrote that they do not collect income data from participants and so could not answer the question.

Both the average participant income and the Medicaid eligibles (43.4%) indicate ADC centers do serve low-income participants.

PARTICIPANT DEMOGRAPHIC CHARACTERISTICS

Category	No. of Respondents	Average
Average Age	718	72.9 years
% Female	764	68.0 percent
Avg. Participant Monthly Income	376	$478
Medicaid Eligible	534	43.4 percent

PHYSICAL LIVING CONDITIONS
(N=776)

Category	% of Total Respondents	No. of Respondents	Average Percent
Living alone in community	80	623	18.8
Living alone in congregate setting (supervised/retirement/senior housing)	66	516	12.3
With spouse, relatives or friends	99	769	63.5
In an institutional setting (nursing home or residential facility)	32	246 (almost 1/3)	4.4

Centers were asked to state the percentage of their participants with specified functional impairments. An assumption made was that by definition an ADC participant would be functionally impaired, be it physical, mental, social or emotional, or the person would not be receiving

adult day care. The survey was designed to identify the most severe forms of impairment. For example, the question of incontinence asked only for the percentage who require changing during the day. Not asked was the percentage of persons whose incontinence is being managed by toileting reminders or a continence training program. If these people were included, the percentage would be far higher. The question regarding wheelchairs asked only for those who transfer only with assistance. Many people in wheelchairs transfer independently. These persons are not included in the data given.

Both the incontinence and the wheelchair questions identify heavy-care participants, as does the category "Need constant supervision." Limitations of center staffing and/or physical facilities may mandate limiting the number or not serving such heavy care persons.

PARTICIPANT FUNCTIONAL CHARACTERISTICS
(N=777)

Category	Respondents	Respondents	Percent
Incontinent (requires changing during attendance day)	62	478	7.8
Cognitively Impaired			
% Needs supervision	92	711	45.4
% Needs constant supervision	76	588	19.8
Developmentally Disabled	56	432	10.1
Behaviorally Disruptive	61	472	7.6
Reliant on Walker/Cane	61	472	17.3
Wheelchair-bound (transfers only with assist)	79	615	12.4

Analysis will be done in Phase 2 to look at the relationship of these functional characteristics to factors

that may influence participant selection, e.g., funding, staffing and services.

Who is Excluded from Participation?

The ability to get along with a group is an important aspect for ADC participation. Although individual services are provided, ADC is essentially a group program. The peer group influence is one of the benefits of ADC. Centers are often not staffed for a one-to-one constant relationship. Persons whose behavior is such that group function is seriously impaired may not be appropriate to ADC.

Centers that target specific populations such as persons with dementia, psychiatric impairment or vision impairments may not accept persons without this particular impairment. Some centers require a certain level of impairment -- such as nursing home eligibility -- for admission.

Eligibility criteria exclusions and their relationship to other factors such as staffing and services will be examined in Phase 2.

What Services Are Provided?

ADC centers were provided with a list of services and asked to indicate how the service was provided -- whether by staff, contract or referral. They were then asked to state whether this service was a budgeted expense and/or an in-kind contribution. Many centers had difficulty understanding distinction between budget and/or in-kind. The

most common misinterpretation was to state all staff-provided services as in-kind, and all contracted services as budgeted. Our assumption is that staff are usually budgeted expenses. To help us decide whether the question was understood, we looked at number of staff and the budget. If we felt the question was misunderstood, the answer was not entered.

Services most commonly provided by staff are social services, nursing, recreational activities, exercises, reality therapy, and dressing/grooming/toileting assistance. A surprisingly high percentage also provide diet counseling, art and music therapy, meals, and transportation (see Table 13).

Contracts were used most often for physical/speech/occupational therapies, transportation and meals.

As might be expected, referrals were most often used for physician assessment and treatment, psychiatry, podiatry, and dentistry, with a significant percentage referring for physical/speech and occupational therapies.

How Much Does ADC Cost?

Centers were asked their current 12-month budget, cost per participant per diem with subsidies and without subsidies, and the type and amount of in-kind contributions.

Annual program budget information was provided by 76 percent (642) of the respondents. The average annual budget was $137,085. The total annual budget was $88,008,500.

The unsubsidized average per diem cost, based on 549 centers, is $27. With the addition of subsidies, the average cost for the 310 centers that reported this figure is $31.

Who Pays for ADC?

In terms of total dollars, Medicaid ($17,830,500), followed by participant fees ($15,387,600), are the two main funding sources. Approximately two-fifths (38%) of the funds come from non-government sources (participant fees, foundations, donations, fundraising, private insurance, United Way, and other) with the remaining three-fifths (62%) from local, state or federal government.

What Are Participants Charged?

When the survey questionnaire was designed, the assumptions were: (1) the charge would be on a per diem basis; and (2) a center would either have one sliding fee schedule or one fixed rate, not both. Both these assumptions were false. Centers may charge by the hour, the day, the week or the month. There may be two sliding fee schedules or fixed rates, and a number of centers have both. In addition, centers may have no charge or accept donations only. Hourly rates were converted to daily rates by multiplying by the average number of hours participants spend at the center. Weekly or monthly rates were not entered. It is obvious that the questions regarding participant charges need revision. Although the intent of

the question was the private pay charge, this was not clear. Reasons for more than one sliding fee schedule and/or fixed rate were sometimes stated -- funding sources may pay different rates, or there may be different service mixes for participants.

Considering that 105 centers stated either no charge or donation only, it is surprising that private pay participant fees are the second largest funding source.

Centers with just one fixed rate (333) average $22.18. For the 34 centers that listed a second fixed rate, the average charge is $31.71.

We are using caution in interpreting the findings of this survey. Although we have summarized the average characteristics of participants and centers, there is great diversity in ADC programs. It is not surprising that variation exists among programs that evolved from the grassroots level, with no national and often no state guidelines. We are pleased, however, to be able to identify the average characteristics of ADC centers nationwide and hope others will find this survey's results helpful in the development of new and improvement of already established centers.